STATE ADVISORY COUNCIL ON PALLIATIVE CARE AND QUALITY OF LIFE

QUARTERLY MEETING

AUGUST 12, 2016 10 A.M.

RSA Tower Board Room 1586 Montgomery, AL

Members Present:

Kristi A. Acker, D.N.P., A.C.H.P.N. - University of Alabama DCH Cancer Center John G. Beard, M.B.A., J.D., President - Home Care Association of Alabama Richard J. Brockman, J.D. - Alabama Nursing Home Association

Beth Caine - Alabama Hospital Association

Stormy Dismuka, C.N.O. Alabama Hospica and Pollicitive Care Association

Stormy Dismuke, C.N.O. - Alabama Hospice and Palliative Care Association Karen Marlowe, Pharm.D., B.C.P.S., C.P.E., Co-Chair - Alabama Pharmacy Association

Rodney O. Tucker, M.D., M.M.M., Chairman - UAB Center for Palliative and Supportive Care

James R. Williams, D., Min., B.C.C. - Baptist Medical Center South Peter Czapla – Alabama Durable Medical Equipment Association

Bureau of Health Provider Standards Staff:

Walter T. Geary, Jr., M.D., Bureau Director/Medical Director Diane Mann, HR Director/Project Liaison LaKesha E. Hopkins, M.S.H.R.M., Assistant to HR Director

Dr. Tucker called the meeting to order. He thanked everyone for coming and asked if anyone had any comments on the minutes from the last meeting. There were none. He then asked for a motion to have them approved. The minutes were approved and there were no corrections or additions necessary.

The first item on the agenda was the linkage to additional national websites in regards to palliative care. Dr. Tucker referenced to the voting on the website linkage that was discussed during the last meeting. The Council voted that there will be links to all of the websites that were suggested during the May 13, 2016 meeting. In addition to those links, Dr. Tucker would also like for the Council members to view HPNA.org and vote during the next meeting on whether or not that link will also be placed on the website.

Dr. Tucker asked if there were any pharmacies or nursing homes that have a link of anything pertaining to palliative care on their website. Mr. Brockman stated he knows they have a link and that he would check on the nursing home side. Dr. Tucker recommended that if anyone had any links from the Hospitals or Nursing Home Association regarding palliative care that would be considered good resources, please share them with the Council. Dr. Tucker added any

information on medication related topics in regards to palliative care or FAQs (frequently asked questions) can also be considered for linkage.

The next topic was the discussion of the Council's Mission Statement. Dr. Geary accepted the task of writing the new Mission Statement and Dr. Tucker asked him to discuss it with the Council. Dr. Geary distributed a handout with the Mission Statement that he created and the one that was taken directly from the Act. He explained that he wanted to make the statement more personable and wanted suggestions and comments from the Council. Once the statements were reviewed, Peter Czapla stated that he thought Dr. Geary had done a very good job with the one he created. Dr. Tucker agreed and stated that the next problem would be what to do about the education program. He commented that we are establishing the website, bringing in consumer information in a standardized way, and accessing ADPH. The next step is to educate through the department about palliative care. This will probably be our mission for 2017. Ms. Marlowe interjected, "After reading the statement, we should have established an information piece." She went on to say "We're going to provide education and perhaps the Council is the way to create a network." Dr. Geary commented that one problem with the department being responsible to educate people is that none of us hold ourselves as experts. Therefore, it will be difficult to be able to present that from a variety of different perspectives as experts. There was discussion about the language in the Act and Dr. Geary felt that the legislature wants physicians and nurses to be more in tuned with what palliative care is. Dr. Tucker commented that he was fine with the Mission Statement the way it is. Dr. Tucker stated that maybe the Council should target professional organizations as part of their educational program. Dr. Geary pointed out that we might be able to use the Department's Video Communication team to make short videos in order to educate the public and reach a younger audience as well. Dr. Tucker asked if it would be possible for them to come to the next Council meeting and show examples of their work. Dr. Geary said that he was sure they would. Dr. Tucker suggested that maybe the ADPH Video Communication Department would like to look at some of the videos that Palliative Care has made to get an idea of what is being discussed.

Dr. Tucker inquired if there were any other comments about the Mission Statement. Mr. Brockman suggested that the Mission Statement should be changed to the following:

The mission of this Council is to promote Palliative Care in Alabama and by improving consumer awareness of the positive effect of compassionate palliative care on the quality of life and care for individuals and families living with life-limiting illness.

This will be accomplished through establishment of a consumer and professional information and educational program within the Department of Public Health; and by facilitating collaboration among palliative care providers, organizations, institutions and individuals.

The entire committee reviewed the changes and agreed that the statement was clear, concise, and the goal of the Council. The changes were voted on, a motion was made, it was seconded and the new Mission Statement was approved.

Kristi Acker covered the next topic of discussion, nursing homes and palliative care. She stated that she has called facilities in the nursing home community and has found that they just opened

the door for palliative care. However, it is mostly geared towards the end of life, not so much palliative care. Dr. Tucker stated that he was interested in knowing what happens to a patient in the nursing home as they deteriorate; terminal. Mr. Brockman discussed the requirements of a nursing home regarding advanced directives and short-term stay. There are really two phases for patients coming into a nursing home; episodic care and transformation. Mr. Brockman discussed how during the care plans phase palliative care, quality of life and end of life can be discussed with patients and their families. Dr. Tucker asked Ms. Acker what she meant by nursing homes are being open to palliative care. Ms. Acker commented that they were open to the in-services and training staff. She went on to say that she would like to make two points. First, the nursing homes do an excellent job in communication and pulling together resources. Secondly, the rehabilitation phase is where palliative care should be introduced. There is not really anything outside of the hospice model and the top concern is developing a network. Ms. Acker added that the top concern that she sees is helping communities develop a network of interdisciplinary team members.

Mr. Brockman stated that one thing to have is an integrated care network. This is a team that follows a patient all the way through, in every setting, regardless if they go home or stay in a facility. Dr. Tucker interjected that this was getting into our additional member discussion which is good because it helps us all be informed. Dr. Tucker stated that what they see on the hospital side is the transitioning into the two groups. They look at their visit as a benchmark and possibly something else happens to the patient enough times that they have to go into skilled nursing. Even if patients go into rehab and have a DNR while there in the hospital, there are a lot of problems as to whether that DNR is honored in a nursing home even though they have it in the hospital. Even when they're told they're better and can go home, there are still issues about staff discussing the DNR. However, when a patient goes into long-term care, different conversations take place, because the needs of the patient become different. The part of palliative care that can make a difference in the nursing home are communication and goals of care.

Dr. Geary asked if there was a national link to palliative care regarding nursing homes and if so what should we look for. Dr. Tucker stated there has been a lot of research done on that subject. Mr. Brockman commented that there is a probably information that we can look at. There was much discussion surrounding DNRs and how they are highly misunderstood. Dr. Tucker concluded that through this discussion the Council was able to see all the different complexities from our vantage point and he considers palliative care the glue that holds everything all together.

Mr. Czapla continued the discussion about how patients are placed in a nursing home because they need "a place to go," and how a lot of them are taken to rehab for 21 days for that same reason. Ms. Marlowe stated because families don't have "a place for them to go" until the family can get some other benefit justified. Ms. Dismuke stated she has two concerns. First, when individuals visit the website, what is available to them in Alabama? She believes there should be a list for each entity on what they offer regarding palliative care. Dr. Tucker commented that Dr. Bakitas explained the "Heart" app could be converted and used as a resource for Alabama. The app has been previously converted and has three applications. Ms. Dismuke's second concern is educating staff on getting medications to hospice patients. Ms. Marlowe agreed that facilities are interested in educating on medications and assessments. She went on to state that facilities are

aware they need the education, but what can be done about it. Mr. Brockman referenced a convention that will be held in September and asked Ms. Marlowe to make a presentation on the early state of palliative care in nursing homes. Dr. Tucker stated that the Council will revisit the subject of palliative care in nursing homes at a later date.

Dr. Tucker also made reference to Hattie Bryant, the author of *I'll Have It My Way: Taking Control of End of Life Decisions: A Book about Freedom & Peace*, and reminded the Council that she is an advocate for patients. He would like to invite her to the next meeting to make a presentation. Also, Dr. Tucker would like to further discuss the "Heart" app and perhaps have the UAB School of Nursing on the phone and the ADPH IT Department present to discuss using the short videos to promote palliative care.

Dr. Geary began a discussion on the form for DNRs. He stated that once the DNR form is in the chart, it serves as the documentation across all entities. This will solve a lot of problems with patients that are terminal and being transferred. Mr. Brockman said a subset of this is that it brings respect to this form and you have to use it and not do anything else. Dr. Geary interjected that now only one physician has to sign the form. He went on to say that people do not understand that by not making a decision, they are really making a decision. Dr. Tucker asked Dr. Geary if the form has been approved. Dr. Geary commented that the form goes before the State Committee on October 3, 2016 and if approved, will become a rule unless there is some type of challenge. Dr. Miller would like for Dr. Geary to make a presentation to the Hospital Association regarding the DNR form. Dr. Tucker thinks the DNR form is a big improvement. Mr. Brockman agreed, it's a huge load off everyone's mind. Dr. Geary commented that the department will not be surveying this form. The burden is on the rules. Ms. Marlowe stated that we are heading in the right direction. Communicating with the family is the best thing to do and families are finally being heard.

The discussion continued in regards to DNRs until Dr. Tucker adjourned the meeting. The next meeting will be on December 2, 2016, at 10 a.m., at the RSA Tower, in Board Room 1586 located at 201 Monroe St., Montgomery, AL 36104.

Minutes	An	proved	d by

Rodney . Tucker, M.D., Chairman

State Advisory Council on Palliative Care and Quality of Life

Walter T. Gearn Ur. M.D.
Bureau Director and Medical Director of Health Provider Standards

Alabama Department of Public Health